**Parents' Initiative in Community-Based Support for Children with Intellectual and Developmental Disabilities: The *Ahada* Non-Profit Model**

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**Funding**: none

**Competing interests**: The authors report there are no competing interests to declare.

**Acknowledgments:** I thank the interviewees who exposed me to the kibbutz cooperative community mutual guarantee and the social entrepreneurs who identified a need, initiated action, and mobilized resources to establish an active organization.

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## **Abstract**

*Background*: The birth of a child with an intellectual or development disability inherently presents challenges to parents regarding the child’s long-term future. This qualitative study examined the perceptions of parents who are kibbutz members, focusing on the non-profit organization they established and the socio-economic model they developed to ensure the future well-being of their children with intellectual and developmental disabilities.

*Methods*: In-depth interviews were conducted with 12 participants and used a thematic analysis based on case study methodology.

*Results*: The socio-economic model developed by kibbutz parents helps alleviate their concerns, but also gave rise to challenges related to kibbutz privatization and the requirement for programs to be tailored to individual needs. The study highlighted how cooperation among families, the community, and government institutions can contribute to individual and collective solutions for people with disabilities.

*Conclusions*: These insights expand our understanding of parental social entrepreneurship within intentional communities and other contexts.

**Keywords:** inclusion, intellectual and developmental disabilities, intentional community, kibbutz

## **Introduction**

Research interest in families with a child with intellectual and developmental disabilities (IDD) and their inclusion into the community has been increasing in recent years (Bredewold et al., 2020; Goodley et al., 2019). This study focuses on a specific scenario in which parents chose to raise their children within an inclusive community and examines the benefits and challenges of this initiative for the parents, the family, and the community as a whole.

Previous studies of intentional communities (IC) have tended to focus on their impact on people with disabilities (Goodley et al., 2019; Randell & Cumella, 2009). Building on recommendations from other researchers to examine social enterprises in the community (Amado et al., 2013; Lumpkin et al., 2018), this study focuses on the social entrepreneurship of parents within a specific type of intentional community in Israel, and the non-profit organization they established to offer lifelong support for people with IDD within that community.

An IC is a type of cooperative community in which a group of people choose to live together and share a certain lifestyle (Oved, 2017). The Israeli kibbutz, first established in 1910, has long served as an example of an IC based on principles of mutual guarantee and the sharing of property and resources (Oved, 2017). Currently, approximately 195,000 people live in 265 kibbutzim, which are located mainly in the geographic periphery of the country (Dar & Getz, 2020). Families of children with IDD in these communities are often distanced from urban centers that offer assisted-living residential facilities to support people with IDD living independently.

This study examines this issue from the perspective of the parents of children with IDD and the communities in which they live. Its goal is to add to the understanding of parental social entrepreneurship in an IC context, and shed light on a unique perspective of inclusion that balances the kibbutz values of mutual support and family commitment. The insights may enhance understanding of the specific case studied here, and contribute to the development of similar models in other communities seeking to promote creative solutions to the long-term challenges faced by families of children with IDD.

### **Literature review: Approaches to the treatment of people with IDD in the community**

People with IDD face significant challenges in the transition from childhood to adulthood, including the sense of being different, the experience of stigma, and difficulty in communication and understanding social nuances (Jansen-van Vuuren & Aldersey, 2020). These challenges can lead to heightened isolation for both the individuals and their families (Power 2008; Wiesel et al., 2024). Yet, while engaging with disability may start at a particular moment, it doesn't stop there, as it is via disability that we can explore a wide range of political, theoretical, and practical issues that are significant for all (Goodley et al., 2019, p. 157).

In the Western world, the treatment of people with IDD has undergone a significant shift, moving away from a medical approach to a social (or non-institutional) approach and more recently to an affirmative (identity) approach (Power 2008; Swain & French, 2000). In December 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities, which Israel ratified in September 2012 (Kanter et al, 2017; Palmisano, 2017). The Israeli government’s commitment to promoting to the full inclusion of people with disabilities, has produced a shift toward freedom of choice and over their own lives. and a shift toward integrating people with IDD in family-like, community-based homes, recognizing that this model is often preferred by many adults with IDD. Yet, the issue of disability often faces legal, administrative, and economic challenges due to the dominance of the medical establishment, which can be resistant to conducting individual assessments and developing solutions tailored to individual needs (Gur et al 2023; Petner-Arrey et al., 2015).

Communities with a diverse population of children and adults, including those with IDD, create a healthy environment for the daily social life of all members (Bredewold et al., 2020; Goodley et al., 2019). Community collective action can provide a supportive environment that enhances social relationships and a sense of security for everyone, including people with IDD (Melucci, 1996). This is even more true of ICs, which aim to provide people with a sense of belonging through the construction of a community identity (Randell & Cumella, 2009).

In ICs, people with IDD and their families find a supportive environment that encourages meaningful living (Author, 2022; Wurf, 2022) by promoting positive relationships, mentoring, autonomy, and social participation (Jansen-van Vuuren & Aldersey, 2020; Randell & Cumella, 2009). Such communities also work to reduce social stigma and improve acceptance (Amado et al., 2013; Goodley et al., 2019). Amplified support for caregivers can help reduce emotional pressure, anxiety, and tensions among parents of children with IDD.

In Israel, the approach to disability still integrates elements of biomedical and rights-based, affirmative models (Almog et al., 2023). Despite legislative changes, some social challenges continue to be framed as medical issues (Gur et al., 2023). Recent trends, however, indicate a move towards community-based rehabilitation with greater parental involvement in educational decisions, alongside progress towards adopting social models (Gur et al., 2023). The Covid-19 pandemic further highlighted the importance of community support services in Israel and globally (Gur et al., 2023; Neece & Fenning, 2020). In Israel, government-funded and NGO-operated services for individuals with IDD include community living programs, day care centers, sheltered workshops, and supported employment programs. The education system offers special education services, including mainstream and separate facilities, while national health insurance covers many medical needs for people with IDD (Almog et al., 2023).

### **Parental initiatives for children with IDD: challenges and solutions**

Researchers have emphasized the effectiveness of family-centered interventions. Those aimed at the well-being of parents of children with IDD are considered critical and address their physical, psychological and socioeconomic needs (Novak-Pavlic et al., 2022; Petner-Arrey et al., 2015; Wurf, 2022). Collaboration between schools and families is also essential for the successful implementation of inclusive practices and enabling smoother student transitions, improving academic achievement, increasing motivation, and reducing behavior problems (Wiesel et al., 2024; Wurf, 2022).

Parents of individuals with IDD often face increased anxiety and emotional stress due to the complexities of caregiving and managing behavioral challenges (Malouf & Dymond, 2023). Families of children with IDD frequently report a lack of sufficient information and resources, which limits their ability to provide effective care, as well as difficulties in navigating complex health and education systems (Wurf, 2023). Parents may struggle to maintain a consistent presence at work (Malouf & Dymond, 2023) as they face the challenge of balancing work and family (Lumpkin & Pidduck, 2018). Therefore, solutions must be suitable for both children and parents.

Many challenges families face concern the transition from childhood to adulthood for individuals with IDD. These challenges impact on learning abilities and emotional and behavioral development, and often lead to delays in social skill development. This may make it difficult for individuals with IDD to interact with peers and participate in group activities (Amado et al., 2013; Neece & Fenning, 2020). The disparities between individuals with IDD and their peers widen, potentially hindering their ability to adapt to an independent lifestyle (Lumpkin et al., 2018; Neece & Fenning, 2020).

Globally and in Israel, targeted community-based programs have been developed for parents of children with IDDs. These aim to address families’ evolving needs in areas like financial planning, abuse prevention, sexuality education, and advocacy training (Almog et al., 2023, Wiesel et al., 2024). They also include parent-led support groups, promoting peer learning, and emotional support (Neece & Fenning, 2020). Additionally, intervention programs provide a community response at home, at school, and clinical settings, with culturally-adapted intervention programs to meet the needs of diverse populations (Kanter & Tolub, 2017).

In recent years, the Covid-19 pandemic highlighted the impact of parental or grandparental loss on a family’s functioning (Neece & Fenning, 2020). This can also result in the need for siblings to take responsibility for a family member with IDD (Brennan et al., 2023). The pandemic, with its forced social isolation, also emphasized the importance of supportive communities (Gur et al 2023; Neece & Fenning, 2020).

### **The Ahada model – a parental alliance for children with disabilities**

Ahada (“compassion”) is a non-profit organization of parents and family members of kibbutz residents with IDD. The Ahada model is a unique example of the combination of a community’s guaranteed support and parental investment to secure the future of a child with IDD. This model has been endorsed by the National Organization of Kibbutz Settlements as the most suitable approach for people with IDDs, which is why we chose to focus on it.

Since the mid-1980s, for economic and demographic reasons, most kibbutzim transitioned from traditional collectivism to a privatized model that combines cooperative and individualistic elements (Ben-Rafael & Topel, 2020). In the current kibbutz model, individual members and their families are responsible for their own economic stability, while the community maintains a cooperative spirit through collective decision-making and the selective acceptance of new members.

Ahada was founded in 1985 during a period of significant change in the kibbutzim. The socio-economic model developed by kibbutz parents aimed to “implement rights and secure the future of children and adults with special needs in kibbutzim” (Ahada website), emphasizing the commitment to the rights and the future of children with IDD.

The original tenets on which the kibbutz was founded were characterized by the mutual commitment of all members to each other, particularly in challenging circumstances such as the birth of a child with IDD, so that the community was essentially obligated to come together and provide support for the person and the family.

Eligibility to join Ahada is based on a number of criteria that include recognition of the child as having IDD by Israel’s National Insurance Institute, the requirement of parental membership in a kibbutz, and the signing of the Ahada agreement. This agreement outlines a course for the kibbutz to take overall responsibility for all the needs of the person with IDD and offers them a place to live for life in the kibbutz. In return, the parents agree to give up their children’s future rights to membership in the kibbutz, effectively excluding them from decision-making processes. Further, the agreement stipulates that the parents’ kibbutz home serves as collateral to ensure the continued support of the kibbutz for the person with IDD, with the property reverting to the kibbutz after the parents’ death. By joining Ahada, parents enter into a socio-economic contract with their kibbutz and guarantee their children’s future, even when they themselves are no longer able to provide them with care. The model positions parents of children with IDD as the main clients in the contract, with the community serving as the entity responding to their child’s needs. Such needs include education, health, housing, and mediation in future conflicts between the family and the kibbutz community regarding the child with IDD (Shay, 2018).

In conclusion, the literature review illustrates the complex challenges that families of people with IDD encounter when it comes to integrating them into the community. Studies have emphasized the importance of family and community support in enhancing quality of life for these individuals. Parental initiative is growing as a creative solution for building supportive frameworks and creating employment opportunities, but these are accompanied by financial and social difficulties.

**Research questions**

Our main research question was: How do parents of children with IDD in kibbutzim perceive the socio-economic model they developed as a source of future security for their children?

Secondary questions include: Does the model answer these needs? What are the main success factors and challenges in implementing this type of socio-economic model in the kibbutz today? Can the principles of the model be adapted and expanded to other community settings as well?

## **Methods**

### ***Research design***

This qualitative research uses a case study approach, which is particularly suitable for studies that seek to understand a phenomenon in depth in its natural context, focusing on a specific “case” (Merriam, 1998). The case studied here is the Ahada model that operates within kibbutzim in Israel. The study attempts to present parental perceptions of the socio-economic model used by Ahada to meet the future needs of children with IDD. The analysis methodology is based on Merriam’s approach to case study while incorporating a phenomenological strategy grounded in the philosophical assumption that “reality is constructed by individuals in interaction with their social worlds” (Merriam, 1998, p. 6). Meaning is generated in the process of interaction and interpretation of the knowledge arising from the research, gaining additional validity through an explanation of the research and its goals as they are described in detail, and a structured analysis for codes and categories (Merriam, 1998).

Due to the sensitive population involved, several ethical steps were taken in this study. First, approval was obtained from the Ethics Committee of our institution. Second, all the interviewees received a detailed explanation of the aims of the study and gave their consent to participate and to have the interviews recorded, transcribed for analysis. Interviewees were informed that they could end the conversation at any time. Finally, to protect their privacy, the names of the interviewees and the names of the kibbutzim were changed. Throughout the process, emphasis was placed on sensitivity, respect, mutual trust, and transparency in the relationship between the research team and the participants.

### **Characteristics of the study participants**

The sample consisted of 12 interviewees: 8 parents and 2 siblings who assumed guardianship of their siblings with IDD after the death of their parents. To gain additional perspectives, we also interviewed a volunteer in the Ahada program who advocates for disability rights, and the head of the kibbutz movement’s health department. Despite the small sample size, the study succeeded in reaching theme and code saturation (Young & Casey, 2018). The age of the interviewees ranged from 49 to 84, and the ages of their family members with IDD from 7 to 62. This study does not include direct perspectives from individuals with IDD, as it focuses on the *Ahada* model as a solution for parents. Future research should address this limitation by incorporating the viewpoints of individuals with IDD.

### **Data collection**

Semi-structured interviews that aimed to uncover the experiences and perceptions of the interviewees in an in-depth and detailed manner (Creswell & Poth, 2017) were conducted via Zoom in March-June 2020. Follow-up interviews were conducted in July-August 2022 to detect any changes, for example due to the Covid-19 pandemic. Each interview lasted 60-90 minutes. An interview guide was used as a basis for the conversation, but allowed participants to introduce new topics, as is typical of the case study approach (for example, see Creswell and Poth, 2017). We focused on: (a) the Ahada model – motivations, feelings, challenges, and coping methods; (b) the family and child with IDD – commitment, the effects of the model on the family and whether it met their needs; (c) interfaces with the kibbutz, the kibbutz movement and interactions with the government, support, required agreements, level of assistance, and difficulties. Relevant letters and magazine articles on *Ahada* and children with IDD in the Kibbutz that mention by the provided by the interviewees were also collected.

### **Data analysis**

The interview transcripts were read several times and the main codes that emerged were marked according to the methodology of Charmaz and Thornberg (2021). Subsequently, a list of codes was compiled relating to the research questions, the characteristics of the research field and the interviewees, and the themes that arose in the interviews. The frequency of the codes was analyzed for different aspects of the model’s activity, reasons for its establishment, advantages and disadvantages, the essence of community relations, and personal perspectives. The analysis categories were determined by linking events, sequences, and narratives together. In the last step, the categories were organized under agreed logical structures and definitions of each central theme as described in Charmaz and Thornberg (2021). The coding process was conducted by two researchers, each working independently. The identified codes were analyzed to form first-order thematic groups, which were then linked together to form second-order thematic groups. The codes and themes were identified and discussed until the researchers reached agreement. This process was continued until overarching themes emerged, thus systematically identifying the connections between the various themes and the response offered by the Ahada model. As members of an intentional community, although not having family members with IDD, the researchers are familiar with the terminology used. This familiarity, while beneficial, necessitated additional reflection when examining the Ahada model as one potential solution for kibbutz communities.

## **Results**

Three main themes emerged from the interviews relating to the need for a long-term solution for parents who are members of a kibbutz and who have a child with IDD. The themes relate to the fact that the family has been thrust into a situation where they must re-evaluate their plans for their present and their future. Additionally, the family is responsible for the care and rights of their family member with IDD, even though they are members of a cooperative community.

### **First theme: A family’s life changes after the birth of a child with IDD**

This theme illustrates how parents recognize and cope with the significant change in their lives. Ron, a parent of a child with IDD, described their family story:

Our second son was diagnosed when he was a few months old […] We organized things so that he could live at home with us […] the whole family rallied, my wife, for example, accompanied Natan to art classes, that’s how he got involved with art and developed his painting.

Ron describes his long and challenging journey as a parent, reflecting how Natan’s birth changed his worldview and his goals as a parent.

We said no, we want him to live by our standards, our norms and in our proximity […] we have no intention of sending him [to an institution, as was the practice until then].

Tammy, a parent of a child with IDD, shared her reflections from the first months following her daughter’s birth. She described the family’s need to adapt their lifestyle and home to accommodate the child’s needs including for physical therapy and transportation. The parents’ desire for their daughter to integrate into the kibbutz’s education system compelled them to fight to gain the kibbutz’s consent and to personally escort the child to school:

Despite my daughter’s severe disability, she spends part of the week here and part of the week in special education […] the children know her and she’s invited to friends and friends come to her.

Tammy had a career outside the home, but transitioned to remote work and became active in the Ahada organization for her daughter’s integration into the kibbutz for the rest of her life.

Two of the research participants, Avraham and Moshe, are siblings of individuals with IDD, now adults. Both described how the dynamics in their home had shifted after the birth of their younger siblings with IDD, as their parents had to focus their attention on the new child. During their childhood, Avraham and Moshe experienced ostracism from children and adults in the kibbutz. Years later, after their parents passed away, they assumed the responsibility of caring for their siblings with IDD. Moshe chose to continue with the Ahada arrangement, while Avraham, facing financial constraints, opted for his sister’s care at a government-funded institution. Avraham said:

The government provides a better and cheaper solution and my sister is happy there...also the fact that I left the kibbutz means that I don’t have to deal with the kibbutz bureaucracy that’s part of the Ahada organization.

From these examples we learned of the ongoing commitment of family, as the second generation takes over responsibility for their siblings with IDD.

Ben, a volunteer tutor in the Ahadaprogram, also described the family tensions that may arise following the birth of a child with IDD. He recounted a case where the challenges contributed to the parents’ separation, after which the mother continued to care for the child as a single parent.

Lea, a parent of a child with IDD, also described the disparities between families caring for a child with a disability:

There are families who come with some kind of human resource that allows them to create this support right from the start and some families that don’t – there are already disparities there. And again, here too, I personally felt how significant it was that we received support right from the first day, which allowed us both to return to work within a reasonable timeframe […] What helped us really were the consultations and the help in exercising our rights.

The disparities in resources and support among the families may complicate the effort to deal with the challenges. At the same time these disparities emphasize the importance of the Ahada mutual agreement to provide a protective umbrella by the egalitarian community.

Tammy and Ron described their efforts to shift the perspective in their kibbutz from sending children with IDD to be “raised in institutions,” to fully integrating them into community life. Tammy spoke of the challenges her family experienced in the kibbutz:

My husband always says, ‘Outside the kibbutz it's so easy for me, I manage to get anything I want... inside the kibbutz everything is so hard, so long, and so exhausting.’

Lea (described the multifaceted changes her family underwent following the birth of her daughter, who has IDD:

There is a struggle on two levels: one is the prioritization of expenses and the other is companionship, simply the continuous emotional support by the family. [...] The very strong feeling I had is that really the kibbutz as a collective community is very, very significant in its ability to generate support for families. [...] From the beginning I had a very strong and very good feeling of community support. There was... when [my daughter] was born there was someone here who was a health and welfare administrator who was very strong and very correct in her attitude, in her approach.

Lea’s comments highlight the immediate financial and emotional adjustments her family had to make, and the crucial role of community support in helping them navigate these changes. Her experience underscored how the birth of a child with IDD transforms not only the family’s internal dynamics but also their relationship with, and reliance on, their community.

The first theme reflects the significant and ongoing change in the life of the entire family following the birth of a child with an intellectual and developmental disability, and the need for special organization and support to help them address the challenges they face. The theme also shows the close link between the family’s internal dynamics and those of the kibbutz.

### **Second theme: a space of belonging – a broad, inclusive concept of the private family home and the public kibbutz home**

This theme concerns the meaning of belonging to a collective community for families with children with IDD, and the relationship between the private and public space of the family and the community. Tammy, a parent of a child with IDD, described the importance of caring for people with IDD as a central value in the kibbutz:

I think the kibbutz communities have done something that no one has done before, and that is to say that we, even legally, stipulate that the kibbutz should take care of people with disabilities. This is […] an obligation that the kibbutz cannot avoid, so it has to prioritize concern for people with disabilities even before the other needs of the kibbutz.

Securing care for people with IDD through the Ahada mutual agreement indicated the deep commitment of the kibbutzim to the value of mutual guarantee and inclusion, even at the cost of foregoing other needs.

Rina, a parent of a child with IDD, emphasized the importance of belonging to the community for her daughter. For Rina, securing the opportunity for her daughter to live as independent a life as possible within the kibbutz community was an important and central goal:

I really, really want her to have the opportunity to live in a kibbutz for the rest of her life, if she wants it, to just live in her own apartment. With two caregivers […] to be an independent person for the rest of her life as much as possible, not to live in some [inferior] place, that’s my fantasy.

In a letter to Ron, Naomi (classmate of Ron’s son Natan, who has IDD) expressed how inclusion, and specifically how Natan had contributed to their shared childhood experience in the kibbutz:

[Natan] taught me listening where there are no words and no shouting […] Only we knew what he meant or what he wanted based on his look or hand movements […] I remember we used to write the numbers on the board and teach him to pronounce them. How we laughed when he would say the number five in the form of a tweet. We laughed with him, we appreciated him for every new word or hand sign he learned [...] When [Natan] would cry, get angry and burst out with frustration, we would melt and feel hurt and anger for him and with him, at the adult who tried to educate him or punish him [...] this is his gift to me.

Naomi described how the presence of Natan in the class taught the other children to be sensitive, to listen, and to see the uniqueness in every individual. Her words demonstrate how the successful inclusion of children with IDD enriched and contributed to the lives of all children in the community. This quote demonstrates how the presence of a child with IDD changes the dynamics of communication in the family and the wider community, requiring the development of new skills and changes in the way people communicate with, and understand each other. The interviewees described how belonging to the kibbutz community created a security and support network for the families and their children.

This theme illustrates how belonging to an inclusive and supportive collective space serves as a source of strength for the parents of children with IDD. At the same time, the presence of children and adults with IDD in the daily life of the kibbutz contributes to shaping the values and character of the kibbutz as a community that is open and sensitive to diversity.

### **Third theme: Ahada as a model for broader society**

This theme discusses the relevance of the Ahada model in the present and in the future, taking into account the transformations that have occurred in the kibbutzim and the perception of disability in society in general. Ben (a volunteer tutor with Ahada), emphasized the importance of a written and binding agreement between the family and the kibbutz as a guarantee for the future of the person with IDD. Ben viewed the legal regulation of the kibbutz’s obligation towards people with IDD as an essential pillar of the Ahadamodel, which must continually adapt to the changing reality:

The main thing that the Ahada organization strives for, and unfortunately has not achieved in all the kibbutzim, is that every child with special needs who is not a kibbutz member should have an express written agreement signed by both parties, the family or representatives of the family and the kibbutz, which guarantees their rights and capabilities and sustenance of the child for the rest of their life. [Such an agreement] is stronger than any regulation and is binding on the kibbutz or any organization that would replace it. If it doesn’t exist then it’s a problem […] a model that is learned and acquired on the fly […] we have adapted it to the changing times and to the new reality that has evolved.

Tammy, a parent of a child with IDD, noted that the Ahada model, despite its advantages, still maintains a certain separation between people with IDD and others, but for her daughter this arrangement works and provides a good response to her unique needs. Tammy said she wished that she “knew the kibbutz was prepared to take care of my daughter for the rest of her life and that she had no obligations towards the kibbutz, but only rights in the kibbutz.”

Meanwhile, Moshe, who became the legal guardian for his sister with IDD after their parents passed away, preferred to rely on government-offered solutions. He noted that these were just as effective as the Ahadamodel, but had the advantage of not requiring the family home to be used as collateral for his sister’s long-term care.

In contrast, Ron, a parent of a child with IDD, explained his preference for the Ahada model over those that offer only economic assistance:

Ahada provides more than just a financial solution. It guarantees long-term responsibility and quality care. With other models, it is not always clear who will take care of our children over the years and what the quality of care will be. Ahada gives us confidence that the community will take care of our children even when we are no longer able to.

Lea, a parent of a child with IDD, described the recent shift to privatization that has taken place in the kibbutzim as a driving force behind economic and demographic improvements. This change has made it possible to renew discussions and reapply the values of mutual responsibility in relation to people with IDD. As happened during the Ahada convention in 2018, Nir Meir, the head of the kibbutz movement: “Every kibbutz needs […] offer all his members and children solutions in the spirit of the kibbutz for a life of dignity, according to the kibbutz's ability.” Meir emphasized That following the recovery of the kibbutzim from the economic crisis, there are more options to address the needs of people with IDD. He pointed out the importance of giving, but also the fact that every kibbutz community is autonomous in its decisions.

Lea highlighted the differences between parents living on kibbutzim and those in other communities when advocating for the rights of their children with IDD. She noted the limited involvement of kibbutz parents in the national movement for the rights of people with IDD and emphasized the need to link efforts inside the kibbutzim to the broader struggle outside the kibbutz framework:

There is a coalition of parents for children with special needs that is very dominant in its activity with government ministries, in the education system, in assimilating awareness about language […] there are very, very strong parents there who lead […] and promote new legislation when necessary. It’s actually something that I regret not seeing from more people in the kibbutzim.

Lea’s statement was supported by another study participant, Yoav Karim, a social activist advocating for people with disabilities. He claimed that injustice exists within the kibbutzim, where decisions are made that fail to uphold the standards of equal rights for people with disabilities as citizens of the country.

Some of the parents interviewed asked, “Shouldn’t Ahada consider this situation and take the children’s opinions into account?” Tammy, for example, called for Ahada to include people with IDD in decision-making processes that concern them and in Ahada’s leadership team. Their personal experience and the difficulties they face are an essential element in the development of the model. Tammy’s thinking attested to the processes that both families and communities undergo, and emphasized the importance of full inclusion and giving voice to people with IDD when designing solutions that suit their needs and desires.

Ron, a parent, recounted the community’s initiative to establish community house association, developed around his son and other young people with IDD in the kibbutz. The community house for 18 adults with IDD and other disabilities (some needing 24-hour nursing care) and a daycare center serving 36 people from 18 regional councils in northern Israel, has been built on land allocated free of charge by the kibbutz. This enables Ron’s son and other children with IDD to live in a supportive kibbutz atmosphere on land provided by the kibbutz, and to integrate with the kibbutz population and its various facilities and workplaces.

The cooperation between the entrepreneurial parents and the kibbutz community has enabled inclusion for people with IDD in everyday life. Ron described the impact of the Ahada model developed in Kibbutz Mahanayim that went a step further in relation to inclusion into the community, and the attitude of the Ministry of Welfare and Social Services:

The representative of the Welfare Ministry told me: ‘Look, you came to us 25 years ago and we didn’t know how to react to you but […] you were right and we were wrong. We won’t build more institutions, we’ll build houses in the community.’ And this is the prevailing perception today.

The success of the “Community House” model in Kibbutz Mahaniyim adapted to solutions far from the center and adopted by the Ministry of Welfare’s perception of the proper way to integrate people with disabilities in Israel.

The third theme pointed out that the Ahada model is not static, but dynamic and evolving, and ongoing discussion is required regarding how to adapt it to social and economic changes in the kibbutz and in society in general, as well as to the unique needs of each individual and family.

Based on the three main themes that emerged from the interviews – the profound impact of raising a child with IDD on family life, the sense of belonging and support provided by the kibbutz community, and the potential of the Ahada model as a source of inspiration for solutions in other communities – our analysis provides in valuable insights into how parents experience and perceive the Ahada model. As illustrated in Figure 1, the thematic figure of the *Ahada* model reflects these central themes and highlights three key anchors: The principle of kibbutz mutual guarantee was found to be a central factor in creating a sense of security and belonging. Long-term planning and economic support led to a reduction in parents' concerns about their children's future. A sense of security for parents of children with IDD, a sense of belonging to the community home, and diversity in the community constitute the practical expression of the model's success, as emerged from the analysis of interviews with participants.

[Insert Figure 1 here]

Figure 1: Analysis findings of a Kibbutz Parents' Initiative Model *Ahada* for Supporting their Children with IDD

These findings form the basis for a broader discussion of the theoretical and practical implications of this unique initiative.

## **Discussion**

This study examines the perceptions of parents of children with IDD living on kibbutzim in Israel regarding the socio-economic model they developed through the Ahada organization. Our findings highlight the multifaceted changes families undergo following the birth of a child with IDD. These experiences align with previous studies that emphasized the importance of family and community support in addressing the unique challenges facing families with children with IDD (Lumpkin et al., 2018; Wurf, 2022). This study extended this understanding by illustrating how the Ahada model, embedded within the kibbutz community structure with its emphasis on mutual support and collective responsibility, has created an adjusted environment for families of children with IDD. It offers not only emotional support but also long-term financial and social security, a crucial need for which there is a lack of provision (Conroy et al., 2016; Gur et al 2023).

The findings revealed that the Ahada model effectively addresses parents’ fundamental needs regarding their children’s long-term safety and well-being while fostering integration within the kibbutz, a key recommendation from researchers (Novak-Pavlic et al., 2022; Randell & Cumella, 2009). This sense of belonging enhances parents’ peace of mind and their children’s quality of life. This aligns with and reinforces previous findings that diverse communities benefit everyone (Bredewold et al., 2020; Randell & Cumella, 2009; Almog et al., 2023). The Ahada model’s focus on the kibbutz’s communal values offers a more comprehensive and sustainable approach to community support, especially important in peripheral areas where IDD support services are scarce.

Consistent with previous research (Author, 2022; Gur et al 2023; Lumpkin & Pidduck, 2018; Wiesel et al., 2024), our findings indicate that the inclusion of individuals with IDD enriches the entire community, fostering empathy, understanding, and a greater appreciation of diversity among all its members.

The Ahada model offers valuable insights for developing supportive frameworks for individuals with IDD beyond the kibbutz setting. Its focus on long-term planning, partnership between family and community, and flexibility in addressing individual needs provides a template that could be adapted to other communities. The success of initiatives like the “Community House” in one kibbutz demonstrates the potential for these approaches to influence broader policy and practice, aligning with recent shifts towards community-based care models (Amado et al., 2013).

However, it is important to acknowledge that the Ahada model has challenges. The ongoing debates about the balance between community and family support and individual autonomy reflect broader discussions in disability studies (Goodley et al., 2019; Malouf & Dymond, 2023; Swain & French, 2000). This tension within the Ahada model provides new insights into the practical application of theoretical concepts, such as those proposed by the United Nations and alternative approaches to living independently and community inclusion (Kanter & Tolub, 2017; Palmisano, 2017).

Our findings also indicate that the Ahada model has not fully embraced the affirmative approach, which prioritizes individual identity, preferences, and rights. The model raises ethical considerations about balancing community support and individual autonomy, highlighting the tension between collective values and individual family needs amid kibbutz privatization. This reflects the evolving kibbutz model (Ben-Rafael & Topel, 2020), and adds a new layer to our understanding of how changing community structures impact support for individuals with IDD.

Like Bredewold et al. (2020), this study highlights the flexibility of the Ahada model. It demonstrates significant adaptability in addressing the diverse needs of individuals with IDD throughout their lives but also reveals rigidity, particularly in decision-making. Major decisions about participation in the Ahada program and long-term care are primarily made by parents or guardians, with limited input from individuals with IDD. This reflects the protective instincts of families and communities, but contradicts modern disability rights frameworks that prioritize self-determination and supported decision-making (Wiesel et al., 2024). It also engages with broader debates on inclusion, protection, and empowerment (Goodley et al., 2019).

The model presents a paradox: while promoting inclusion and support, it also fosters exclusion from full community membership. Despite its benefits, the Ahada model falls short of upholding equal rights for individuals within the kibbutz (Dar & Getz, 2020). Its structure, requiring parents to relinquish their child’s future kibbutz membership rights for lifelong care, creates a distinct status for individuals with IDD and infringes their families’ inheritance rights within the kibbutz.

The issue of continuity in long-term care, especially for siblings who have left the kibbutz, adds complexity. While Brennan et al. (2023) examined evolving sibling dynamics following the death of parents, our findings extend this within the kibbutz context, highlighting the interplay between family dynamics and community structures in long-term care planning for individuals with IDD. Paraphrasing Winnicott’s (1965) notion of being a “good enough” parent, and Lee’s (1985) insights on fostering children’s development in a secure and supportive family environment, one could argue that the Ahada model reflects the need for a “good enough family living in a good enough community.”

This study has several limitations. First, the sample includes a relatively small number of participants, which makes it difficult to broadly generalize the findings to other communities. Second, the study focuses on the parents’ perspectives and does not include those from people with IDD or other members of the kibbutz community. This decision stemmed from ethical and practical considerations. While the kibbutz context may limit the generalizability of these insights, the depth and richness of the qualitative data provides valuable insights applicable to other contexts. Follow-up studies can build on this by exploring the subject from additional angles, using larger and more diverse samples.

## **Conclusions and recommendations**

The Ahada model shows how integrating community values with parental initiatives can create a comprehensive support system for individuals with IDD. This study reveals how the unique characteristics of the kibbutz community, in particular mutual guarantees and social solidarity, can be leveraged to address the long-term needs of individuals with IDD and their families. While rooted in the kibbutz context, the principles of long-term planning, community integration, and economic support embodied in the Ahada model offer valuable insights for developing similar initiatives in other community settings. The model fosters a sense of belonging and security for individuals with IDD while enriching the broader community, highlighting the potential of community-based solutions for addressing the complex challenges faced by individuals with IDD and their families.

Policymakers and practitioners should draw on models like Ahada when developing support systems for individuals with IDD, focusing on long-term planning, community integration, and ensuring flexibility for diverse and changing needs. Balancing community support with individual autonomy and preferences is essential. By applying these insights, we can create more inclusive, supportive communities that improve quality of life for all, including those with IDD.

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